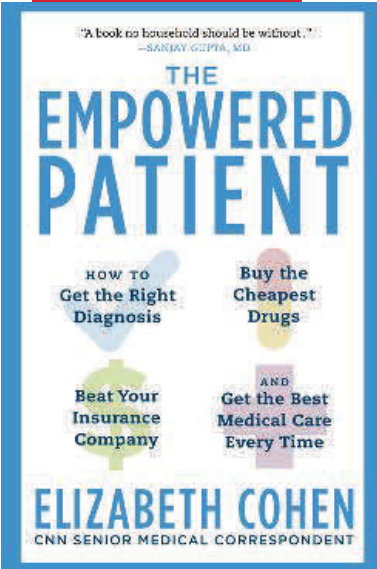


The Empowered American Patient



The landscape of today’s nearly \$3 trillion healthcare industry is complex to say the least. Patients are increasingly at the center of this complex American healthcare ecosystem— empowered and informed by new tools and resources.

The ubiquity of technology, legal reform in the Affordable Care Act (ACA), rising costs, and patient accountability of healthcare are just some of the drivers behind a shift in the American patient from being passive to empowered. These drivers are impacting the patient’s relationship with Health Care Professionals and approach to healthcare management, including more control over treatment approaches.

In this white paper we seek to understand in more detail the drivers of the patient-centered healthcare ecosystem.

Doctor Recommended

The paternalistic model of the physician-patient relationship of thirty years ago, whereby passive patient relied explicitly upon the physician’s expertise for guidance, has been completely turned on its head. Today, patients have increasingly become more of a partner with their physician.

Having said that, a study reported by [the Journal of the American Medical Association](#) found that a patient has only 23 seconds to describe their medical complaint before being interrupted by their physician. Compound this with the introduction of electronic health records in the office, whereby doctors input data on the computer during consultation, and a visit to the doctor’s office is becoming more impersonal. Nor is it memorable for the patient; [up to 80% of the medical information](#) patients receive from their doctor is forgotten immediately and almost half of what is retained is inaccurate. There seems to be a major disconnect in the information transfer between patient and physician.

It’s not surprising then that according to a [2013 Cisco Customer Service Report](#) focused on healthcare, 74% of respondents were open to virtual doctor visits.

Elizabeth Cohen, daughter of two physicians, was inspired by her own personal patient empowerment through the traumatic birth of her daughter. Spurred on by what she saw as the failings of a broken medical system, she set out to empower other patients through this book and her “Empowered Patient” column on CNN.com

The virtual Dr. is in!

Patients with everyday health and medical questions can use **HealthTap** to crowdsource responses from the pool of 14,000 licensed U.S. physicians.

Patients get real-time assistance with a doctor, anytime with **Ringadoc**.



The Self-Reliant Patient



Dr. Charles Safran

In testimony before the House Committee on Ways and Means's Health Subcommittee in 2004, Dr. Charles Safran, President of the American Medical Informatics Association said;

"In our country, patients are the most underutilized resource, and they have the most at stake. They want to be involved and they can be involved. Their participation will lead to better medical outcomes at lower costs with dramatically higher patient/customer satisfaction."

Symcat.com: This web-based app utilizes a data-based approach to online symptom searching. A series of questions regarding symptom and duration of discomfort then elicit responses from accredited Center for Disease Control data.

"A google for your health symptoms"

- The Atlantic

Today's emphasis on patients' overall health and wellness, and highly personalized care, is further encouraging patient empowerment and accountability. A patient's more active role in decision making, fueled by greater access and consumption of healthcare information, is a true testament to that.

The access to diagnostic and treatment information, in part a result of online resources such as WebMD, has equipped patients to take action regarding their health. According to a recent [Pew Research Center survey](#), 35% of US adults have used the internet to diagnose a medical problem for themselves or someone else. Search engines such as Google, Yahoo! or Bing have been consulted for diagnostic information by 82% of Americans. Of those seeking out information online, 46% found advice online which led them to believe they needed further medical advice from their doctor while 38% said they could self-treat.

Today, patients deliberate treatment choices with much more information and advice beyond their physician than ever before. They arrive at the doctor's office laden with questions, suggestions, and informed hypotheses to discuss with their physician. 41% who sought information online first were confirmed in their initial diagnosis by their doctor. According to [Prevention's 2012 DTC Study](#), patients requesting their doctor prescribe medicine they'd seen advertised was 24%, up from 19% of respondents in 2010. Of those patients who request a specific drug, 76% will receive that prescription from their physician.

This empowered American patient strongly believes in the power of medical testing and cutting-edge treatment options. Among five focus groups of insured, healthy, middle-aged Americans, (in a study funded by the [Selz Foundation](#)) participants placed significant importance on screening and testing and reacted with disdain to recommendations by medical guidelines for less of either.

What must be pointed out, however, is the danger in minimizing the role of the doctor. In patients' increased role of responsibility for their own health, they lack the doctor's expertise and depth of knowledge to make the best decision possible.



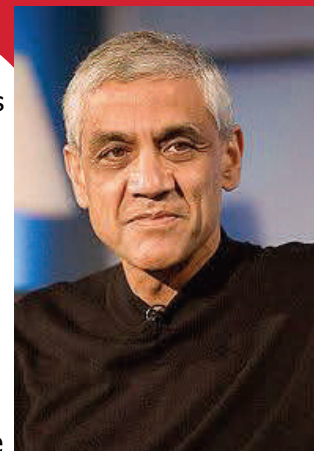
Technology's Impact on the Patient; The Quantified Self

Technological and telecommunication innovations, including bio-monitoring devices and tools, and online forums, further fuel the emphasis on patient empowerment. With the huge amount of information available online today, the rules of the healthcare industry are being rewritten—and it's all about data. It is projected that in 2015, the world will produce data in the amount of 120,000x the total of all previously written words in history; and healthcare information is a huge part of big data. The federal government's appreciation for open data in healthcare is demonstrated by its recent praise of MedRed, a Washington, D.C.-based healthcare software company, and BT's, a UK-based telecommunications company, launch of a new open data health cloud. This data will be used "to provide an overall picture of a patient's health," Neal Stine, principal consultant at BT.

Many people are also interested in harnessing and reviewing their own health data by wearing bio-monitoring devices and using health tracking apps. These "self-trackers" believe that by collecting and reviewing data about their daily activities, they will be able to improve their lives (aka "body hacking" or "self-quantifying"). The 16.2 million wearable devices and wellness/fitness apps consumed in America in 2011 are anticipated to grow to over 93 million in 2017.

Accelerometer and altimeter equipped devices, such as *Jawbone* and *Up*, allow for movement data collection which can be used to analyze anything from physical activity to sleep patterns. The downplayed but revolutionary M7 chip in the new iPhone 5S will allow for the use of gyroscope, compass, and accelerometer sensors without noticeably draining the battery—undoubtedly inviting many more 'Quantified Self' apps to operate on the new system. "The Quantified Self" blog, started in 2007 by author and journalist Gary Wolf, led to meetings and eventually conferences in 50 cities around the world where this topic takes center stage: This is truly a growing community.

Currently tens of thousands of patients around the world are already sharing information about their symptoms and treatments for many conditions. Open source healthcare resources and sharing platforms such as *PatientsLikeMe*® and *Cure Together* enable users to connect and share with other patients.



"Health care must be more data driven and about wellness, not sick care."

"Eighty percent of doctors could be replaced by machines."
- Vinod Khosla, co-founder of Sun Microsystems



**Join PatientsLikeMe® Today and
Find RARE Patients Like You!**



The RARE Open Registry Project™ is a partnership between Global Genes Project and PatientsLikeMe®.



The Affordable Care Act (ACA) and Rising Cost of Healthcare

With this year's implementation of the ACA, major changes are occurring in the approach to healthcare solutions for many Americans. There are some significant points to highlight which shift the burden of responsibility to the patient.

Personal health accountability is encouraged within the ACA wellness provision "outcomes-based programs:" Requirements include that individual workers attain or maintain specific goals, which then are measured by biometric screening or questionnaire.

Concurrently, with the rise of Accountable Care Organizations, "a doctor's compensation model is shifting away from fee-for-service to pay-for-performance." says Zoe Barry, CEO and Founder of ZappRx, a healthcare startup that combines e-prescribing with mobile payment technology. Simply put, this means that physicians will require more information from their patients in order to obtain reimbursements from Medicare.

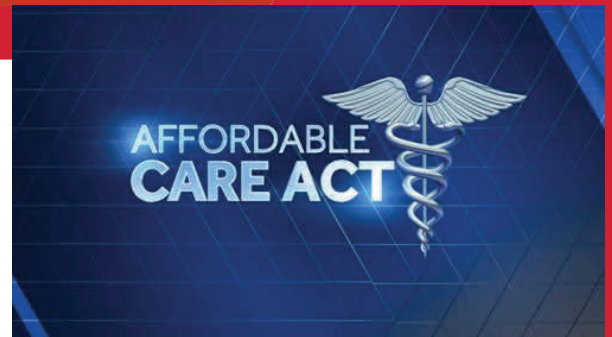
With average in- and out-patient deductibles rising two fold since 2009, alternate care options (virtual doctor visits, etc.) are increasingly more efficient and cost-effective for Americans. According to a Forbes study, only 26% of respondents replied they're very confident their organization will offer health insurance in 10 years. According to a Mercer survey on the ACA implementation, 12% of all employers said they'll reduce some workers' hours to limit health insurance eligibility.

One way that patients are combating the rising cost of healthcare is by taking generic versions of brand-name prescription drugs. According to the FDA, 80% of prescriptions filled in America are generic and on average cost 80-85% less than their brand-name counterpart. The consumption of generic drugs is expected to increase as a number of popular drugs are slated to come off patent through 2015.

"The health insurance industry is undergoing a major shift as it struggles to find ways to control costs. The PPACA may help, but cost control is not a single-solution problem. The industry has put increasing focus on helping people help themselves, providing tools for them to live healthier lifestyles, potentially reducing the need for healthcare."

-Robyn Kaiserman, Financial Services Industry Analyst

As patients continue to navigate the complex healthcare system of the ACA, and the accompanying ACO operating model, an increasingly more accountable and empowered patient-centric approach is emerging.



"Healthcare is expensive because the healthcare system is expensive and we need to manage that cost"
- Ruthann Laswick,
President, Blue Water
Benefits Consulting

ACO Operating Model



